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HRSA Care *ACTION*

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U.S. Department of Health & Human Services
HRSA
Health Resources and Services Administration

November/December 1999

HRSA Care*ACTION*

PROVIDING HIV/AIDS CARE IN A CHANGING ENVIRONMENT

HIV Disease in Adolescents

Introduction to the November/December Issue

In this issue of HRSA Care Action we endeavor to provide an overview of HIV disease among adolescents. Our objectives are to summarize the issues that every individual serving young people should understand, and to point readers in need of more in-depth information to a variety of resources available in print and on the web.

There are an estimated 40,000 new HIV infections in the U.S. annually; 25% of them, or some 10,000 infections, are believed to occur in youth ages 13 to 21. Despite the efforts of HRSA, CARE Act providers, and organizations and individuals across the country, relatively few HIV-infected teens are currently receiving care.

Most HIV-positive adolescents will remain unaware of their serostatus well into their twenties, unless we become more successful at outreach, prevention, and meeting basic health care needs. Therefore, renewed attention to the epidemic among the nation's youth is important.

Applying what has already been learned is an essential first step. More productive solutions to the problems that separate youth from health information and health care are also needed. Ultimately, integration of HIV education, counseling, and testing into primary care and making primary care a norm rather than an exception are crucial if we are to dramatically reduce the incidence of HIV among adolescents in the third decade of the AIDS epidemic in

HIV Care for Sexual Minority Youth

Background

During the late 1980s and early 1990s, researchers found that although gay male and bisexual youth were at high risk for HIV infection, few disclosed their sexual orientation to health care providers, because they did not feel safe. Consequently, providers assumed that most of their lesbian and gay youth clients were heterosexual.

Fear that their confidentiality would not be maintained and lack of knowledgeable, sensitive providers were recognized as common barriers to care for lesbian and gay youth. Poor access to HIV counseling and testing was an additional problem for those at risk for HIV. These concerns, together with a dearth of information on primary care for this population, prompted HRSA to convene a conference on their primary care needs in December 1994. Participants developed the first clinical care protocols for primary care, mental health and HIV related medical and psychosocial care for lesbian and gay youth. More recently, a follow up guide, Lesbian & Gay Youth: Care & Counseling, was published by the American Academy of Pediatrics' Adolescent Section Journal and Columbia University Press. Implementing these care guidelines is a second critical step in addressing the care needs of sexual minority youth.

Sexual minority youth face the tasks of managing a stigmatized identity from a very early age, often without family or peer support.

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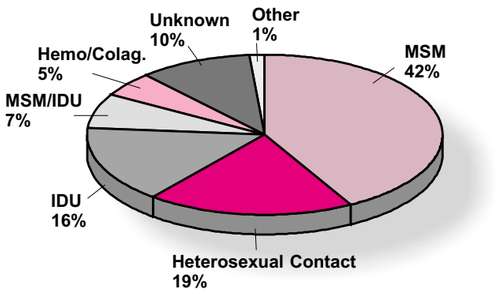
IN THIS ISSUE

HIV Disease in Adolescents and Risk for Seroconversion

Seroprevalence

Historically, 17% of reported AIDS cases have been diagnosed among individuals in their twenties; given the period from seroconversion to AIDS — ten years on average — it is clear that most were HIV-infected while in their teens. This data, combined with the estimate that one quarter of new infections occur among individuals under 21 years of age, can leave no doubt that HIV disease in adolescents is a significant public health problem.

AIDS Cases Diagnosed in Individuals Aged 13-24 (Cumulative)[1]



Gender

Compared with adults, females represent a much higher proportion of reported AIDS cases among adolescents and young adults: 55.5 percent in individuals ages 13-19 and 40.5 percent in those ages 20-24, compared to 23 percent of cases among all adults and adolescents.[1] There are several reasons why:

- *The sexual partners of young girls tend to be boys who are older.*
- *Because of the immature cervix, adolescent girls have heightened risk for sexually transmitted diseases (STDs). Their occurrence increases risk for HIV infection and the need to see a provider who may recognize the need for an HIV test.*
- *Fewer adolescent boys than girls receive counseling and testing, although data suggest that their seroprevalence rate is higher. At publicly funded sites in 1996:*
  - *— The number of females 13-19 years of age who were tested was 2.5 times greater than the number of males in the same age group.*
  - *— Among those tested, the seropositive rate in young males was twice that in young females (0.4 percent and 0.2 percent, respectively).[2]*

Access to Counseling and Testing

Adolescents of both genders are the most medically underserved of any age group.[3] They face very high barriers to HIV counseling and testing, including:

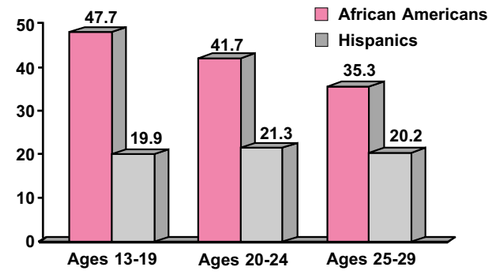
- *poor access to youth-appropriate testing facilities,*
- *cost of testing,*
- *lack of awareness of HIV, and*
- *the belief that they are not at risk.[4]*

Results of one random-sample national telephone survey of 400 individuals from 15 to 17 years old showed that 25 percent had been tested for HIV, although 42 percent had had sexual intercourse.[5]

Young men who have sex with men face additional barriers. Low self-esteem, the inability to have an honest relationship with their health care provider, and the fear of being exposed as a gay or bisexual man are all major problems.

Adolescent males are also unlikely to be tested for HIV infection because they are less likely than females to see a clinician, since they do not have the reproductive health concerns that cause their female counterparts to seek medical care. Thirty five percent of the few cases diagnosed among young men in their teens have been among those with hemophilia or another coagulation disorder — in other words, among young men who needed to see a clinician for a non HIV-related health problem and who demonstrated a known risk factor (hemophilia) for HIV.

Proportion of Total AIDS Cases Among African Americans and Hispanics[1]



Predictors of Risk

Sexual Activity Among Adolescents in School

- *37 percent of 9th graders in the U.S. and 66 percent of 12th graders have had intercourse.[6]*
- *Sixteen percent of sexually active youth report having had more than four partners.[7]*
- *Over one million teenagers become pregnant annually.[8]*

> *Adolescents not in school*
> *From 10 to 15 percent of adolescents are not in school. Academic failure and dropping out of school is associated with risk for home-lessness, mental illness, addiction and a host of additional problems including teen pregnancy, physical illness and HIV. Very little information is available on sexual activity in this population.[10]*

Early Sexual Activity Among Young MSM

Young men who have sex with men are especially vulnerable to HIV infection. Lack of safe places to socialize, lack of accurate information about sexuality and risk behaviors, and increased potential for having partners who are HIV-infected increase their vulnerability.

The Young Men's Survey, a venue-based probability survey conducted in the San Francisco Bay area in 1994-1995, found both an above average HIV seroprevalence rate and alarmingly high levels of high-risk behaviors. Overall seroprevalence was 6.2 percent; the rate for African Americans was over three times that for whites (13.3 percent versus 4.3 percent respectively). In one six-month period:

- *65.6 percent of respondents had more than one sex partner;*
- *24.9 percent had unprotected receptive anal intercourse;*
- *24.6 percent had unprotected insertive anal intercourse;*
- *78.5 percent engaged in unprotected oral intercourse;*
- *53.3 percent had sex when "high".*

Of those who tested positive in 1994 or 1995, 71 percent had tested negative previously (median time from prior test was 11 months).[9]

Sexually Transmitted Diseases

The presence of certain STDs increases susceptibility to HIV, particularly among females:

- *Two-thirds of the 12 million STD cases reported each year are in individuals aged 25 or younger; one-fourth are among teenagers.*
- *46 percent of reported cases of chlamydia — the most prevalent reported disease of any kind in the country — occur in female adolescents aged 15-19.*

Socio-Economic Factors

Poverty is associated with a series of problems among adolescents. They include: abuse, academic failure, little opportunity for social advancement, substance abuse, early sexual activity and sexually transmitted diseases—including HIV disease. The interplay between these problems requires a comprehensive approach. Provider experience has shown that, without addressing the immediate results of growing up in poverty, effective intervention and prevention of HIV is elusive.

> *Poverty in Adolescents*
> - *One of seven adolescents in the United States lives in poverty.*
> - *One of every two minority adolescents lives in poverty.*
> - *One in three impoverished minority adolescents has no medical coverage.*
> - *Nearly five million adolescents are unin-*

Continued on Page 4

Continued from Page 3 . . . HIV DISEASE IN ADOLESCENTS

Substance Abuse

Substance abuse strongly influences behaviors that increase risk for HIV transmission. It also decreases the probability that HIV-positive adolescents will be reached through outreach, tested, and linked to care.

- *One-third of high school youth report having had five or more alcoholic beverages at least once in the prior month; more than 25 percent report smoking marijuana; 16 percent report using inhalants such as industrial solvents, paints, and nitrates.*[11]
- *Heroin use among teens has nearly doubled since 1991, and nearly 1 in 50 high school students report having injected an illegal drug.*[12]

Homelessness in Youth

The rate of HIV infection is higher among homeless youth than in the general U.S. population.

- *One study conducted in three adolescent clinic settings in San Francisco (n=1254) found a sero- prevalence rate of 3.0 percent. Of these three clinics, one served homeless youth specifically; the seroprevalence rate among its clients was 9.3 percent .*[13]
- *A New York City study (n=2667) in a facility for homeless and runaway youth found 5.3 percent to be HIV positive.*[14]
- *A recent survey conducted in among homeless youth in Hollywood, CA (n=96) reported a HIV seroprevalence rate of 11.5 percent.*[15]

Youth in Corrections

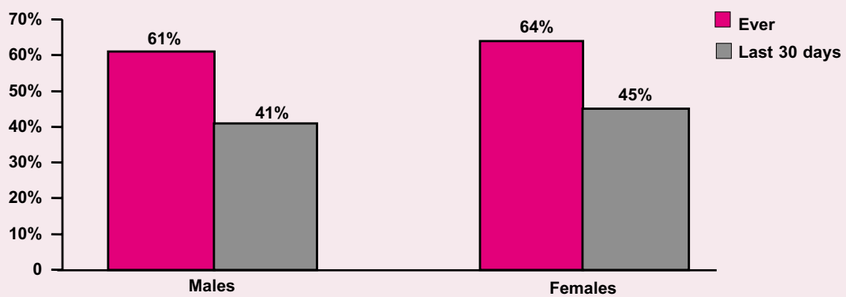
Results from seroprevalence studies among youth in corrections from the early 1990s vary widely — from 0 to 4.2 percent.[16] *Few more recent data are available.*

In a survey of state and local juvenile justice detention centers, most of the 73 respondents did not have information regarding the number of youth with HIV disease in their systems, or the number who were HIV-positive upon release. STD rates were high: 2 percent for syphilis, and 14 percent for gonorrhea. Two of the systems had mandatory screening for HIV, and most provided STD, HIV and pregnancy testing on a voluntary basis, or when clinically indicated.[17]

A list of resources on adolescents and HIV disease may be found on the web at www.hrsa.gov/hab. References for this article may be found on page 12 of this publication.

RYAN WHITE CARE ACT DATA BITE

Youth Reporting Unprotected Sexual Intercourse
Special Projects of National Significance
Adolescent Initiative



The Adolescent Initiative was conducted from 1994 through 1996 in10 project sites across the country. These data have been assimilated from project evaluation activities. Sexual activity was reported for 1931 males and 1904 females.

INTERVIEW

Adolescent Care: A Clinician's Perspective

Dr. Lawrence J. D'Angelo is Medical Director of the Burgess Clinic at Children's National Medical Center in Washington, DC. The Clinic is the oldest and largest organization caring for adolescents living with HIV disease in the Washington area. It is funded by a variety of sources, including the Ryan White CARE Act.

Currently, the Burgess Clinic provides comprehensive care to 105 clients through a team that includes physicians, nurses, nurse practitioners, case managers, health educators and mental health professionals.

How do HIV-positive children and adolescents learn about the Burgess Clinic?

Dr. D'Angelo: The clinic is linked with a variety of community-based outreach programs identifying kids who are at risk. We also have our own outreach activities.

The problem is that many adolescents are not being reached by these efforts. Some stumble into care when they present for other health reasons. But, rarely do we see kids who have gone to a practitioner in the community who has said to them, 'Say, you're participating in behavior that might put you at risk for HIV infection. I want to test you for HIV.'

"Most kids don't get into care the way that we would hope — through a good screening mechanism that identifies children and young adults at risk, provides appropriate counseling and testing, and links HIV-positive individuals with a coordinated system of care."

Who are your patients?

Dr. D'Angelo: While the overwhelming majority of our patients have acquired their infection during their teen years, a growing number were infected perinatally. With HAART, we are bringing lots of kids who would previously not have survived to age 12 into adolescence very successfully.

Two-thirds of the patients at the Burgess Clinic are females. But, it's important to remember that two-thirds of all out-patient adolescent patients at Children's National Medical Center are female. This is largely because young females have gynecological concerns that make medical care necessary. Therefore, they typically enter the medical care system earlier than males.

Of all segments of the U.S. population, adolescent males are the group least likely to get medical care. And virtually all the young men we have in care are sexual minority youth, so they are even further marginalized from mainstream care.

What are the differences in disease progression between adults, adolescents and children?

Dr. D'Angelo: We are still learning what all of the differences are.

In the mid-1980s some studies indicated that adolescents with HIV infection sustained them-selves better than older individuals with similar CD4 counts. Other studies suggested that disease progression is more rapid in adolescents. There are a variety of countervailing reasons for this lack of agreement.

On the one hand, perhaps adolescents are, overall, healthier. Their immune status is better; they have fewer concurrent infections like CMV, hepatitis B, herpes simplex, etc.

On the other hand, adolescents are more susceptible to certain viruses. For example, "Who gets infectious mononucleosis, the clinical syndrome?" Adolescents do. The Epstein-Barr virus (which causes mononucleosis) behaves in many ways very much like the HIV virus, and so perhaps there is something in the adolescent immune system that makes them more susceptible to HIV.

"HIV infection creates a whole realm of problems for adolescents in terms of their growth, their potential, and in coping with their own sexuality. What do you tell a 15-year-old kid who wants to be active sexually and has had HIV infection since birth? How do you instruct them? It's complicated, and it's very challenging."

Continued from Page 5. . . ADOLESCENT CARE: A CLINICIAN'S PERSPECTIVE

There are other aspects of adolescence that influence susceptibility to HIV. Adolescent females, for instance, are at much higher risk of acquiring a whole variety of sexually transmitted diseases just because of the type of cell that lines their genital tracts. This changes as they grow older.

We've had an opportunity recently to participate in a national study — called the REACH study — that is going to allow us to answer these types of questions. Remember, though, we're answering these questions 20 years into the epidemic.

"Perinatally-infected children, with what in adults would be relatively robust CD4 counts, can be catastrophically ill."

What has the Burgess Clinic experience shown about maintaining continuity of care for adolescents?

Dr. D'Angelo: For many who have acquired the infection during their teenage years, the disease is, unfortunately, the least of their problems. These are kids who have suffered all kinds of deprivation: emotional deprivation, physical deprivation, and sexual exploitation. These are kids who have already lived five lifetimes worth of difficult and unpleasant things by the time they're 15 or 16 years of age.

Having said that, we find that many are remarkably responsive to a caring attitude and are really excellent patients. This may be surprising because the knock against adolescents is that you'll never get them to take their medicine. Of course, we have kids who are very responsible about caring for their disease and kids who aren't. But the same is true of adults.

Ironically, there's some benefit from poor adherence in the past. We've begun to do a resistance study in our patients. And even though we've had patients who've been "on medication" for 8 or 10 years, they are still amazingly responsive to treatment. One of these kids is 19 years of age. She acquired her infection perinatally, and she should have been resistant to every antiretroviral medicine known to man. Instead she's totally susceptible to treatment and, consequently, I don't think she has taken meds as prescribed until now. When she began HAART she had a viral load of four million; 2 weeks later it was 17,000, This dramatic improvement has been sustained because she's finally able to adhere to her treatment regimen.

"One of our clients isn't on HAART because she doesn't want anyone except her mother to know about her HIV infection. She is afraid that with medication bottles around the house others will find out.

What kind of social support network do your clients typically have?

Dr. D'Angelo: The majority of the kids that we see actually do have some sort of family network. It may not be a family network in the way many people define family, but it's family for them – whether it's their group home and their group home counselor, their aunt or uncle, or their grandparent.

We are actually very lucky. We're continually told that the family is threatened in this community, but District of Columbia residents have been remarkably resourceful in redefining their social networks in such a way to provide support. Our case managers become part of that. Our clinicians become part of that. Our nurses and nurse practitioners become part of that as well, and this is one of the reasons that providing care to adolescents is so labor intensive.

But, some of these kids are so isolated that even if they're living at home, their families don't know about their disease. Or if their families know, certainly nobody else in the neighborhood does because the entire family could be ostracized. There is still an extraordinary stigma attached to HIV. Is it better than it was? Yes. Are we where we should be? Absolutely not.

"What we try to do is to reverse the natural tendency to say: 'Get lost, we don't want to care for you. You're too difficult to take care for. It's too negative an experience for me to watch you not take your medicine'."

How can we encourage adolescents to accept treatment?

Dr. D'Angelo: I never know when the teachable moment is going to be.

I saw one of my patients the other day for a college physical. This is a kid who dropped out of high school and had been living on the streets — I'd completely lost contact with her for a 2-year period of time. She called me a week before her physical. I knew that 6 months prior she had had a baby. She'd shown up in the obstetrician's office 8½ months pregnant.

Her baby was treated at birth and subsequently with AZT and is HIV negative. The young mother has become a n absolute model patient. She looked at me and said, 'Taking care of myself is now the most important thing because who's going to care of my son.' There has been a renaissance in this young woman. She's going off to college, and she's moving in with her parents who want to help her care for the child.

You never know when that switch is going to be thrown.

Serving Adolescents: The Fundamentals

Findings from the SPNS Adolescent Initiative

Background

In 1994, $2.7 million was awarded over three years through the Special Projects of National Significance (SPNS) Program to support the development, evaluation and replication of improved methods of providing care to HIV-positive adolescents. The environment for launching the program was one in which the care needed by HIV-positive adolescents often was not available, awareness of the problem of HIV among adolescents was not widespread even among providers, and the knowledge base for design and implementation of youth-appropriate programs was limited.

Ten heterogeneous projects were funded for a period of 3 years, each designed to meet the needs of a specific youth population at the local level. These programs improved the lives of the adolescents they served and illuminated program characteristics essential for serving youth effectively.

Collectively, the 10 SPNS Adolescent Initiative projects enrolled more than 5,400 adolescents at high risk for HIV; 654 were already HIV positive. These numbers are significant since many program grantees started from ground zero. The 10 projects do not represent the entire array of CARE Act programs serving young people, but their findings indicate the fundamental elements of successful youth-centered programs.

SPNS Adolescent Initiative Findings

Provider service mix and interagency collaboration

- *Providers must firmly establish which services they are going to provide. HIV-positive and at-risk youth have many diverse needs and one agency is rarely equipped to address them all.*
- *Collaboration between agencies is essential, but establishing and maintaining linkages often proves difficult. While the number of providers capable of serving adolescents has increased in some cities, in many it has not: in rural areas, youth-centered services remain almost non-existent. Forging an effective network of care requires relationship-building resources; yet community-based organizations are commonly understaffed. Adolescent Initiative experiences confirm that providers who keep HIV-positive adolescents in care overcome these barriers to interagency collaboration.*

Know Your Client Base

Every client base is unique. One Adolescent Initiative grantee conducted a focus group among its clients and discovered:

- A preference for female providers;
- Race of the provider was not an issue;
- Sexual orientation was an issue — heterosexual youth preferred that their care provider also be heterosexual (or a "closet" gay) while gay youth preferred an openly gay provider.

These findings were then reflected in the grantee's services and staffing.

Recruiting and retaining youth in programs

- *Referrals from other service organizations and outreach in a variety of venues are necessary for reaching adolescents. Opening the doors and waiting for youth to come will not work.*
- *After attracting youth, establishing trust is critical to keeping them in care. Initiative findings indicate that peer-based outreach and counseling are effective tools, and that recreation and socialization activities with other youth and adults are*

Continued from Page 5. . . SERVING ADOLESCENTS THE FUNDAMENTALS

- *Respect and confidentiality are equally important. Teen clients want respect from program staff and practitioners, and they expect it to be manifested in quality of care. Confidentiality is a paramount concern, even to the extent that some adolescents are leery of translators. If clients do not perceive that they can trust their providers and that their confidentiality is protected, they will not stay in care for long.*

The 10 SPNS Adolescent Initiative Projects

Teenage Access Project
University of Alabama at Birmingham
Birmingham, AL

Adolescent/Young Adult Planetree Program
Walden House, Inc.
San Francisco, CA

Bay Area Young Positives, Inc.
San Francisco, CA

Childrens Hospital Los Angeles
Los Angeles, CA

Health Initiatives for Youth
San Francisco, CA

TOPS Project
Greater Bridgeport Adolescent Pregnancy Program
Bridgeport, CT

Indiana Youth Access Project
Indianapolis, IN

Boston HAPPENS Program
Children's Hospital Corporation
Boston, MA

University of Minnesota Youth & AIDS Projects
Minneapolis, MN

YouthCare Project
Seattle, WA

Addressing immediate needs and overcoming barriers

Basic human needs

- *Pressing needs such as shelter and food take precedence over HIV, and must be addressed by providers before other care issues. Startlingly, one Initiative program reported that some homeless adolescents indicated that they wanted to become HIV positive because they believed that they would then receive health services and support.*

Mental Health

- *Conquering psychological barriers to accepting HIV care and heeding prevention messages is a major problem, and one that all providers must help their clients address. At-risk adolescents commonly have a poor self image, and thus are unlikely to see the need for either HIV testing or a modification of "risky" behaviors. Some adolescents are especially prone to "magical thinking," the belief that HIV infection can't happen to me. Others are often susceptible to hopelessness and fatalism, and may have problems with drug and alcohol abuse.*

  To be effective, programs must teach youth to value themselves, which can be achieved through:

  - *Establishing peer support groups to reduce stigma and isolation of HIV positive youth;*
  - *Providing or linking with substance abuse treatment programs for youth; and*
  - *Offering non-judgmental support.*

Adapting to Adolescent Needs

- *Perhaps the most fundamental finding from the Adolescent Initiative is the importance of keeping the focus on youth. Accordingly, staff must be willing to adapt expectations and modify tactics to conform with the level of maturity and priorities of adolescents.*

- *HIV-positive and at-risk adolescents comprise a heterogeneous group. Programs must be adapted to the adolescent subpopulation they serve. For example, street youth are often illiterate or read at no higher than a fourth grade level; this must be reflected in printed materials they receive. If the provider serves several subpopulations, they need to provide services accordingly. This might be manifested in individual support groups for gay and bisexual males, youth recovering from substance abuse, and HIV-positive adolescent mothers.*

- *Adolescent Initiative experience indicates that youth generally have a high level of unmet need and that serving them is expensive. Because of the number and complexity of issues facing HIV-positive and at-risk youth, more intensive case management generally is required. Youth may need frequent reminders of appointments and further support in terms of access and transportation. They often require help with housing or*

- *Flexibility is crucial when serving adolescent clients. Programs need to offer services at times and locations convenient to youth. This may mean performing intakes in the evenings or on weekends, or off-site at shelters used by adolescents.*

- *Modifying program entry requirements also is important; providers have found that adolescents often are unable to fulfill a level of commitment that, for adults, might not be taxing. For example, one Initiative program found that young female clients were anxious to participate in a risk-reduction group, but were unable to attend the standard six sessions. In response, the provider developed a "mini" curriculum that could be covered in 2 hours.*

- *Successful programs provide youth with the opportunity to be involved in all aspects of project activity. Most successful SPNS projects (8 of 10) had youth on staff in positions ranging from peer outreach to program planning and management.*

Managing and supporting staff

- *Emphasis must be given to building the team, transitioning youth into staff/management roles, and supporting staff with training and fringe benefits. All staff require the opportunity for advancement.*

- *Initiative results indicate conclusively that, as staff members, youth can be effective in any number of roles. But youth need more supervision and more on-going support than older staff. They may be doubly challenged by becoming isolated from others in their age group and simultaneously lacking the support of adult staff who do not consider them peers. They need a peer support network outside of their work. Further, the youths' skills must appropriately match program needs.*

To find out more about the Adolescent Initiative, visit www.TheMeasurementGroup.com/HIV_KB.htm

HIV/AIDS Bureau Adolescent Projects

Adolescents are served through all CARE Act programs, but the HIV/AIDS Bureau is also involved in special initiatives that target this population. Three important activities are described below.

- *REACH — Reaching for Excellence in Adolescent Care and Health — is a collaborative effort of HRSA, NIH and several adolescent care sites across the country. The objective is to better understand HIV disease in youth and to design and implement mechanisms for bringing them into care.*

- *Five grants totaling $2 million annually have been awarded specifically to improve networks linking counseling and testing, primary medical care, support services, and clinical research. The goal is to increase the number of HIV-positive youth receiving care in youth-sensitive environments. Recipients are located in Puerto Rico, Chicago, New Orleans, San Francisco, and Boston.*

- *In the context of the Special Projects of National Significance Integrated Services Initiative, three additional grants are being used to develop and evaluate mechanisms for serving adolescents with multiple needs. These are being implemented in Newark, Miami, and Chicago*

Continued from Page 1. . . HIV CARE FOR SEXUAL MINORITY YOUTH

Health Concerns

Sexual minority youth experience the same physical health and mental health concerns as their heterosexual peers. They additionally face the tasks of managing a stigmatized identity from a very early age, often without family or peer support. Isolation—a common reality for many gay youth—affects them cognitively, socially, and emotionally, with significant implications for health outcomes, including risk for HIV infection.

Because health prevention and promotion literature rarely mention sexual orientation, non-heterosexual youth may view them as irrelevant. Unlike their heterosexual peers, gay youth lack safe places to socialize in supervised, alcohol and drug free environments. And because many health providers still assume that patients are heterosexual, they do not ask about sexual identity. Moreover, they provide little or no information on behaviors that increase risk for STDs and HIV.

Regardless of sexual orientation, adolescents may engage in same-sex behavior, putting themselves at risk for STDs, including HIV. By creating a nonjudgmental environment where adolescents feel safe to disclose health problems and concerns, providers can address the needs of all adolescents, including those of non-heterosexual youth. Providers can let teens know that they are comfortable with any concerns the youth may have by including visual cues in their offices and waiting rooms, such as posters, brochures and books about sexuality, substance abuse, and HIV (see resource list for an excellent poster on issues of concern to teens).

Adolescents and HIV: Outreach and Care

Sexually active gay and bisexual male adolescents, especially gay youth of color, are known to be at high risk for HIV infection, yet HIV counseling and testing is still not readily accessible as a routine part of adolescent care. Nonetheless, HIV counseling and testing is a gateway to care for HIV-positive youth. It also helps reinforce HIV prevention strategies for uninfected youth.

HIV counseling and testing is still not readily accessible as a routine part of adolescent care.

Although some may wrongly believe that adolescents do not want to get tested and do not want providers to ask personal questions, teens actually prefer having providers initiate discussion about HIV prevention and testing. Proactive testing strategies are especially important to non-heterosexual youth, particularly those who are reluctant to disclose their sexual identity. Adolescent outreach strategies must respond to the reality that youth who actively seek HIV counseling and testing may be perceived to be gay. For such youth, fear of disclosure, and ensuing discrimination and harassment serve as a barrier to testing and receiving care.

Resources for Sexual Minority Youth

Wildflower Resource Network
Poster for offices and waiting rooms:
"This is a safe place to talk about..."
P.O. Box 3315
Bloomington, IN 47402

Advocates for Youth
Information on health and HIV prevention, support and community resources.
http://www.youthresource.com/

Gay & Lesbian Adolescent Health Resource Center — 718-882-0322
Clearinghouse for provider training on health, mental health and HIV/AIDS care for sexual minority youth. Adolescent AIDS Program, Montefiore Medical Center, adolaids@aol.com

National Youth Advocacy Coalition — 202-319-7596
Referrals to support groups, supportive services and providers around the country.
http://www.nyac@nyacyouth.org

Youth Guardian Services — 703-361-6909
Online support for sexual minority youth and youth with sexual minority family members
http://www.youth-guard.org

Improving Access to Information and Counseling and Testing

The enormous disparity between the number of HIV-infected youth and the relatively few who are currently receiving care continues to receive attention from HRSA. Services to sexual minority youth are currently available through all CARE programs. In addition, the agency is participating in special projects that will increase understanding of HIV disease in youth, and result in better care for this population. For example, HRSA is partnering with other agencies and organizations to financially support the replication of a youth-oriented counseling and testing campaign developed by the Adolescent AIDS Program at Montefiore Medical Center (a recipient of CARE Act funds). Using social marketing strategies and pro-active peer outreach, the campaign: 1) helps youth associate sexual activity with the need for HIV counseling and testing; and 2) creates a new paradigm for a continuum of care — from prevention and care). Critical components include: youth oriented messages and language; peer leadership and involvement in outreach; and active community networking and outreach to providers.

Goals for Primary Care

A primary concern for all adolescents with HIV infection, regardless of sexual orientation, is adjusting to their HIV status. Access to support services and psychosocial care is especially important. Overall goals for primary care include:

1. *determining the stage of HIV disease and health status;*
2. *providing ongoing health maintenance for HIV and primary care needs;*
3. *monitoring immune function and viral load;*
4. *providing access to state-of-the-art treatment;*
5. *providing education on HIV and risk reduction;*
6. *identifying and addressing psychosocial needs; and*
7. *providing access to appropriate clinical trials.*[1]

Because treatment and care must accomodate an adolescent's developmental stage and cognitive capacity, providers need to create an individualized treatment plan. Guidelines are available for providing routine counseling, testing, and care to adolescents in primary care settings.[2] *It is imperative that clinicians consult these resources so that they may overcome their own barriers to recognizing risk for HIV, and discussing health care issues with sexual minority youth .*[1,3,4]

References for this article may be found on page 12.

YOUTH HOPE 2000

The Ryan White National Youth Conference on HIV/AIDS

Over 600 youth activists will meet on February 19-21, 2000 in St. Louis for the Ryan White National Youth Conference on HIV/AIDS. Past conferences have addressed HIV education in the public school system, health education through the Arts, sexual minority youth health, living with HIV, and confronting racism. The year 2000 conference will see increased emphasis on treatment and skills- building for young people living with HIV. Concurrent tracks will include:

- *Power of Prevention (peer-based education)*
- *Our Communities, Ourselves (serving specific subpopulations)*
- *Getting it Going (advocacy and skills development)*
- *Supporting Our Youth (training adults who serve youth).*

The conference is a project of Metro Teen AIDS, an HIV-prevention organization in Washington, D.C., the National Association of People with AIDS (NAPWA), and the Ryan White Foundation. Sponsors include: HRSA, CDC, The National AIDS Fund, and Roxanne Laboratories.

Youth registration (before December 1, 1999) is $110.00, and includes conference materials, meals, and hotel for the duration of the conference. For information, contact Sara Leedom at NAPWA, 202-898-0414, ex.126, or e-mail, sleedom@napwa.org.

Streamlining of CARE Act Data Reporting

Revision of the aggregate mandatory data reporting systems for CARE Act grantees and providers is underway. Early this fall HAB constructed a single draft data reporting data-reporting instrument for Titles I through IV. The form was distributed to all grantees, and approximately 100 have provided feedback . Currently, the Bureau is reviewing grantee input, as well as that received from other Federal agencies and concerned organizations. After the review process is complete, a final draft instrument will be constructed and presented at the All-Titles meeting slated for January 2000 in Washington.

The effort to simplify CARE Act data collection and reporting is driven by the need to improve capability for measuring program impact. Number of clients served, demographic profiles, insurance status, stage of disease, and provider characteristics are just some of the descriptors for which more complete data is needed. Also important is a decrease in the administrative burden borne by CARE Act grantees, particularly organizations funded through several Titles and currently required to meet disparate data reporting requirements for each.

Although the official deadline for submitting input on the draft data reporting instrument distributed to grantees has passed, individuals may still provide feedback by contacting Alice Kroliczak, Project Director, at Akroliczak@hrsa.gov.